

## **Executive Summary**

The dramatic growth in the number of children affected by autism spectrum disorders (ASD) now constitutes a public health crisis. Throughout the state of California, families and systems of care are struggling to meet the needs of individuals with ASD across their life span. The California Legislative Blue Ribbon Commission on Autism was established to identify the gaps in programs, services, and funding for ASD and develop recommendations to the State Legislature and Governor Arnold Schwarzenegger to address these gaps.

Pursuant to Senate Concurrent Resolution 51 (Perata), Resolution Chapter 124, Statutes of 2005, the California Legislative Blue Ribbon Commission on Autism presents this report of its findings and recommendations to close the gaps in programs, services, and funding for Californians with ASD and their families.

To fulfill its charge, the Commission established a statewide forum and process using task forces, town hall meetings, and other approaches to obtain input from families and other ASD stakeholders. The Commission's findings and recommendations reflect significant gaps that warrant action and could serve as a roadmap for further change. Creating a seamless system of comprehensive programs and services for ASD would require a significant investment of resources that are not currently available. Therefore, many of the Commission's recommendations promote the development of successful models through demonstration projects and other targeted efforts so that effective approaches can be expanded when additional resources are available.

## **Summary of Findings**

The Commission identified specific issues that currently impose serious barriers and challenges to the health and well-being of individuals with ASD and to the support needed by their families. These specific findings and gaps are presented and described in detail within each of the subsequent chapters. Each chapter also contains pertinent background information and proposed goals and objectives for state policy.

Many of the issues are evident for individuals with ASD and their families across their life span and involve multiple systems of care. Thus, the Commission's findings of major "overarching" gaps are summarized as follows:

1. There is a significant number of children with ASD who have not been screened, assessed, or referred to early intervention services in an appropriate and timely manner. These delays are longer and occur with more frequency in underserved populations and communities.
2. In many communities, public awareness, education, and outreach efforts on ASD programs and services must be intensified and expanded.
3. Many existing systems of care are very complex, and a significant number of families confront major barriers in accessing and navigating programs and services. Transitions across systems and programs are especially difficult for children with ASD at age three. In addition, families report problems accessing ASD services through their health insurance coverage.
4. There are many ASD programs and services that require greater coordination and integration to comprehensively and effectively serve individuals with ASD throughout their life span.
5. Many ASD programs are often categorical in nature; therefore, eligibility criteria and the types of services offered may vary across the state.
6. Many ASD programs and services could be improved by the availability of additional resources, infrastructure, and supports to meet the needs of all individuals with ASD and their families.
7. Many ASD programs and services would benefit from the availability of additional professional and paraprofessional development and training.
8. Some ASD programs that involve the public and private sectors require clarification about the roles and responsibilities of each group that provides ASD services.
9. In many regions of the state, some programs, services, and persons who are involved with and respond to specific emergencies, such as medical and public safety responders, require additional information and training on ASD.

10. Many programs that provide services to individuals with ASD and their families could benefit from additional resources and assistance to promote effective strategic planning, communication, and collaboration between service agencies and consumers and their families, and thereby also avoid contentious disputes.
11. Some highly effective programs and services for ASD should be identified, analyzed, evaluated, and replicated throughout the state.
12. Throughout the state, there is an intense need to plan for and address the impending housing, transportation, employment, and educational needs of the “tsunami” of young people with ASD who will soon transition into community settings.

## **Summary of Policy Recommendations**

The Commission was charged with analyzing the existing gaps and providing policy recommendations that would begin to address these issues. The recommendations are related to the three key areas identified in Senate Concurrent Resolution 51:

- Early identification of ASD;
- Education and treatment of children, adolescents, transitional youth, and adults with ASD; and
- A comprehensive and integrated continuum of programs, services, and funding required to address the “aging out” of children who comprise the current autism epidemic.

The policy recommendations related to the three key areas are outlined in Chapters 2 through 8 of this report and summarized here as follows:

**EARLY IDENTIFICATION AND INTERVENTION** Establish a demonstration project at multiple sites that will serve as a template to expand early identification programs. The demonstration project should focus on distressed communities; ensure the timely diagnosis of and intervention for children with ASD; improve collaboration among providers; provide support to families and caregivers; establish a seamless system for service delivery between regional centers and local education agencies; and promote smooth transitions across programs for children with ASD from birth to kindergarten (Chapter 2, page 19).

**HEALTH INSURANCE COVERAGE** Enact legislation, regulations, and other policies to ensure appropriate and equitable coverage for ASD by private health plans and insurers (Chapter 3, page 29).

**THE ASD PUBLIC HEALTH CRISIS** Implement a statewide public awareness campaign on ASD linked to innovative efforts by the California Department of Public Health to improve access to and navigation of programs and services for ASD (Chapter 4, page 37).

**EDUCATION OF CHILDREN WITH ASD** Address the need to increase the number of teachers, paraprofessionals, and other school-based personnel trained in education of children with ASD (Chapter 5, page 45).

**RESOLUTION OF SERVICE DISPUTES** Empower families and local education agencies to collaborate in establishing appropriate and effective individualized education programs for children with ASD. Have the state of California conduct a comprehensive and independent review of the process for resolving service disputes and identify and promote effective dispute resolution models (Chapter 6, page 53).

**NEEDS OF YOUTH AND ADULTS WITH ASD** Expand postsecondary educational opportunities and establish new and effective career technical education models, including intensive support, for individuals with ASD. Expand innovative community-based approaches to supported employment, transportation, social-recreational programs, and housing for the ASD population (Chapter 7, page 61).

**AWARENESS OF ASD IN EMERGENCY SITUATIONS** Provide training and information on ASD to peace officers, first responders, allied judicial public agencies, and emergency response systems (Chapter 8, page 65).

## **Conclusions and Next Steps**

The Commission urges the State Legislature and Governor Schwarzenegger to adopt these recommendations by enacting legislation the Commission will offer for the next legislative year. The ensuing legislative discussion must include a comprehensive fiscal review and analysis of current state spending on programs and services for ASD and the impact of the Commission's recommendations.

The Commission also urges state policymakers to make ASD an important public policy priority during the next three to five years. As part of an ASD public policy agenda, there should be greater coordination in planning and policy development across the state agencies that have key roles and responsibilities for helping Californians with ASD and their families.

Given the Commission's time frame, it was not feasible to address all issues identified by families and other ASD stakeholders. The following important issues warrant further analysis to identify appropriate solutions:

- There is an insufficient number of developmental pediatricians, speech and language therapists, behavioral therapists, occupational and physical therapists, psychiatrists, psychologists, neurologists, and other health care providers to provide services to individuals with ASD.
- Low-income Californians who receive health and mental health care services through the Medi-Cal Program experience serious problems locating primary care and other health care providers with ASD expertise.
- A diagnosis of autism does not entitle children and youth who are full-scope Medi-Cal eligible and under age 21 to receive specialty mental health services through county mental health plans under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit.
- There is a need for long-term quality assurance and monitoring of the efficacy, or alternatively any specific risks, of the interventions and treatments provided to individuals with ASD.
- The needs of older adults with ASD must be addressed in a comprehensive way as the ASD population, their parents, and other caregivers for this population age.
- There is a far-reaching problem of inadequate compensation and other incentives for service providers across systems of care to serve persons with ASD and other special needs.

During the year ahead, the Commission looks forward to working with state policymakers on the recommendations and other issues identified in this report.